Transition between Primary and Specialized Care in monitoring systemic arterial hypertension: restricted access and discontinuous care

Transição entre Atenção Primária e Especializada no acompanhamento da hipertensão arterial sistêmica: acesso restrito e cuidados descontínuos

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Abstract

This study aims to analyze access to specialized care and continuity of care in the experience of users with systemic arterial hypertension in the transition between levels of care. An evaluation study was carried out based on interviews with users referred by primary health care to specialized care. From the thematic analysis, three moments were identified that reflect participants' experiences. The first is the request for a "referral for specialized care," identified by users as "documents," which obstruct access to therapeutic support and generates dissatisfaction with primary health care. To "access specialized care," users and family members forged different strategies, parallel or complementary to the use of public services. The barriers were more significant for specialized exams: around ¾ of users sought them in the private network, especially in popular clinics. The "continuity of care" dimension offered no communication between care levels, where users themselves transmitted clinical information, compromising the coherence of care and fraying bonds, which failed to be established in primary health care and specialized care. The experiences of transition between levels shows restrictions and mitigation of full access to health with impacts on credibility and satisfaction with the public health system.

Keywords: Health Services Accessibility; Continuity of Patient Care; Comprehensive Health Care; Niterói.

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Resumo

O objetivo é analisar o acesso à Atenção Especializada (AE) e a continuidade do cuidado na experiência de usuários com hipertensão arterial sistêmica (HAS) na transição entre níveis assistenciais. Foi realizado estudo avaliativo a partir de entrevistas com usuários encaminhados à AE pela Atenção Primária à Saúde (APS). A partir da análise temática, foram identificados três momentos que refletem as experiências dos participantes. O primeiro é a solicitação da "referência para AE", identificada como o "papel" que obstaculiza o acesso à retaguarda terapêutica e gera insatisfação com a APS. Para "acesso à AE", usuários e familiares forjavam diversas estratégias, paralelas ou complementares ao uso dos serviços públicos. As barreiras foram mais expressivas para os exames especializados: cerca de ¾ dos usuários buscavam na rede privada, sobretudo em clínicas populares. Na dimensão "continuidade do cuidado", não havia comunicação entre níveis assistenciais, de modo que as informações clínicas eram transmitidas pelos próprios usuários, comprometendo a coerência da atenção e esgarçando os vínculos, que não se estabeleciam na APS e na AE. As experiências de transição entre os níveis revelam restrições e mitigação do acesso integral à saúde, com reflexos na credibilidade e na satisfação com o sistema público de saúde.

Palavras-chave: Acesso aos Serviços de Saúde; Continuidade da Assistência ao Paciente; Atenção Integral à Saúde; Niterói.

Introduction

Cardiovascular diseases are the leading cause of death worldwide (Brunier; Muchnik, 2020). In Portuguese-speaking countries, for example, systemic arterial hypertension (SAH) and dietary factors were the factors that most influenced disability-adjusted life years (DALYs) lost due to cardiovascular diseases (Nascimento et al., 2018). In Brazil, the 2019 National Survey on Health (PNS) indicates a prevalence of self-reported hypertension in 23.9% of the population, higher among females, older adults, and people with low schooling (Malta et al., 2022).

SAH is one of the main modifiable risk factors for cardiovascular disease, chronic kidney disease and a range of other conditions. The implementation of health policies that increase access to primary and secondary prevention actions with early detection and control of SAH in Primary Health Care (PHC), together with guaranteed treatment of acute events, are essential for the control of cardiovascular diseases (Malta et al., 2022; Nascimento et al., 2018). In Brazil, studies show that the consolidation of coverage by the Family Health Strategy (FHS) was associated with a reduction in mortality from cerebrovascular, heart, and cardiovascular diseases (Rasella et al., 2014).

The Brazilian National Health System (SUS) is responsible for caring for around two thirds of people with SAH, the majority in Basic Health Units (UBS – *Unidade Básica de Saúde*) and the rest in Emergency Care Units (UPA – *Unidade de Pronto Atendimento*), according to data from the PNS (Malta et al., 2022). According to Brazilian guidelines, regular monitoring and the search for adherence to drug and non-drug treatment are functions and challenges for PHC, even if the diagnosis was made at other points of care (Brasil, 2014).

Although there is no robust evidence as to the most appropriate time, people living with SAH who do not reach their target blood pressure, after ruling out lack of adherence to follow-up in PHC, can be referred to specialized services (Brasil, 2014). Furthermore, some users are referred to Specialized Care (SC) without a clinical indication. A study carried out in a medium-sized Brazilian municipality showed that 38% of users referred to SC did not meet clinical criteria, and 1/4 of them were not hypertensive, suggesting problems in monitoring SAH and weaknesses in the dialog between the different levels of care (Vanelli et al., 2018).

The transition of care between PHC, SC, hospital and intersectoral care is recognized as a critical stage in care trajectories, especially for complex cases that require multiple and integrated interventions (Baxter et al., 2018; Hudon et al., 2022). "Integrated care models" aim to increase coordination between services, actions, and health professionals, as well as having positive effects on perceived quality of care, access, and user satisfaction, without necessarily increasing the use of specialized services (Baxter et al., 2018).

The transition between different sets of care involves a group of actions to ensure coordination and continuity based on comprehensive plans, availability and integration between professionals and providers, logistical arrangements (e.g. transportation), sharing of clinical and social information and information about user and family preferences (Coleman, 2003; Khatri et al., 2023). With regard to the population living with SAH, comprehensive, multi-professional and continuous care and the centrality of PHC in management and follow-up are positively associated with reducing morbidity and mortality and promoting health (Dantas; Roncalli, 2019; Malta et al., 2022).

This article aims to analyze the dimensions of access to SC and continuity of care for users diagnosed with SAH in the transition between care levels. Access to SC is considered a major organizational and supply bottleneck in the Brazilian public system, with repercussions on the general appreciation attributed to the SUS (Cecilio et al., 2012). Continuity of care is related to how users experience the coherence, logic and timeliness of the care offered by different health providers (Haggerty et al., 2003). It is an expression of integration, coordination, and accessibility, as it favors the use of necessary services and satisfaction with the care received (Haggerty et al., 2003). Analyzing elements of users' transit across care levels can provide important evidence for the production of less solitary and fragmented care trajectories, often traced on the margins of the SUS. Furthermore, it is in the provision and use of the set of actions provided for in the line of care that the principle of comprehensiveness is realized.

Methodology

This is an evaluative study with a qualitative approach, based on semi-structured interviews with users diagnosed with SAH, registered in Family Health (FH) units in the municipality of Niterói/RJ and referred to SC for consultations or tests. The use of a tracer event for SAH is justified insofar as the condition has a high prevalence, diagnostic criteria, and defined interventions with a recognized influence on the course of the disease (Kessner; Kalk; Singer, 1973). Furthermore, understanding users' experiences is an important step and can inform improvements in the implementation of policies, services, and actions that are synergistic to integrated care (Almeida; Casotti; Silvério, 2023).

The study was carried out in Niterói, in the state of Rio de Janeiro, a pioneer in the reformulation of PHC in Brazil. In the early 1990s, inspired by the Cuban model, whose basic team consisted of a doctor and a nursing assistant, it implemented the Family Doctor Program, primarily aimed at covering the population in Areas of Special Social Interest, characterized by high vulnerability (Lacerda, 2022). At the start of data collection, in February 2022, 84 FH teams were working, covering 33.7% of the population. The main reference point for SC was 7 regional municipal polyclinics. Table 1 shows some socioeconomic, demographic, and health indicators that express municipal development—such as the high HDI and GDP per capita—and, at the same time, intraterritorial inequalities—such as the Gini Index and the fact that almost 30% of the population has a per capita income of up to ½ minimum wage (Table 1).

A total of 38 in-person interviews were carried out from February to July 2022, by researchers with a background in public/collective health and trained according to the research objectives and instrument, in 10 of the 43 UBS. The criteria for selecting the UBS were: (1) those with the highest number of FH teams (ranging from 3 to 6); and (2) distribution by regional health district. After selecting the UBS, the participants were identified by the interviewers with the help of the FH teams according to the inclusion criteria: having a diagnosis of SAH and being registered with a FH team; having had a referral request from the PHC for a consultation or specialized examination in the 12 months prior to the interview (checked in the medical records or log books); being over 18 years old; not having any physical or psychological impairment that would prevent the interview from taking place.

Table 1 - Socioeconomic and health characterization. Niterói, Rio de Janeiro, Brazil, 2022

Socioeconomic characterization	Indicators
Population (inhab.)(1)	481.749
Population density (inhab./km)^2(1)	3,601.67 inhabitants/km^2
Gini Index(2)	0.598
MHDI(2)	0.837 (very high)
Life expectancy at birth (inhab.)(3)	Women – 80.30 Men – 71.19
Average monthly salary of formal workers(1)	3 minimum wages
GDP per capita(1)	R$ 128.333,01
Population with nominal monthly per capita income of up to 1/2 minimum wage (%)(2)	29.5%
Literacy rate of people aged 15 and over(1)	98.2%
Extremely poor population (%)(4)	0.80%
Population benefiting from the Bolsa Família Program (%)(4)	15.98%
Health resources	
FHS coverage (%)(5)	33.72%
Number of Family Health Teams(5)	84
Number of Basic Health Units(6)	43
Population coverage of supplementary health care (%)(7)	56,2%
Regional specialty polyclinics(6)	7
Saúde na Hora (5)	0
Infant mortality rate(1)	11.4 deaths/1000 live births
Hospitalization rate for hypertension (%)(8)	14.4 per 100,000 inhabitants
Proportion of people with hypertension with a consultation and blood pressure measured in the semester(9)	4%

Source: (1). IBGE, 2022; (2). IBGE, 2010; (3). Atlas Brasil, 2024; (4). Ministério do Desenvolvimento e Assistência Social, Família e Combate à Fome, 2024; (5). Brasil, 2024; (6). Niterói, 2024; (7). Secretaria Estadual de Saúde, 2024; (8). UMANE, 2024; (9) SISAB, 2024.[1]

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[1] For more information, check the sequence of sources below the table: Censo Demográfico do IBGE (2022 e 2010); Atlas do Desenvolvimento Humano no Brasil (2023); Painel Bolsa Família e Cadastro Único (2024); E-Gestor Atenção Básica: Informação e Gestão da Atenção Básica (2024); Secretaria Municipal de Saúde. Portal da Saúde de Niterói (2024); Indicadores de Saúde Suplementar - Taxas de Cobertura no Rio de Janeiro (2024); Observatório Saúde Pública (2024); Indicadores de Desempenho, Previne Brasil (2024).

Participants were contacted and invited to come to the UBS if they were available or had an appointment, or they were asked if they could be interviewed at home. When the interviews took place at the UBS, the participants' privacy was guaranteed. The interviews were conducted by the article's authors and guided by a semi-structured script. The script went through a pre-test stage and was organized into the following blocks: sociodemographic profile, habits, time since diagnosis of SAH, experiences since discovering SAH and paths taken in the search for health care in public and private services. This article focused on the transition between PHC and SC.

The average duration of the recordings was 30 minutes, and the respective audios were transcribed in full. The sample was closed based on two criteria: (1) theoretical saturation (Glaser; Strauss, 1967), suspending the inclusion of new participants when the data began to show repetition and convergence in the researchers' opinion; and (2) distribution of the interviews in all the regional health centers in the municipality.

Thematic analysis of the content of the interviews was carried out to identify and describe patterns or themes, following quality assurance criteria such as: complete and inclusive coding of each interview; selection of relevant excerpts grouped into themes; and interpretative analysis of the data (Braun; Clarke, 2006).

Thus, three dimensions were identified which reflect the participants' experiences in the transition between levels with regard to both access to SC and continuity of care of users with SAH. These dimensions were conceptualized based on documentary and bibliographic references that guided the presentation of the results (Box 1).

The study was approved by the Research Ethics Committee of the Institute of Human Sciences of the Universidade Federal Fluminense (Opinion No. 4.456.756), with the consent of the municipality. The participants signed an Informed Consent Form and were identified by the letter P, followed by numbers according to the sequence in which the interviews were carried out, gender, and age. The names of the health services have been omitted.

Chart 1 - Description and conceptualization of the study's analysis dimensions

Dimension	Description
Referral to specialized care	In order to operationalize the Health Care Networks (HCN) in Brazil, referral systems—from PHC to the other levels of care—and counter-referral systems—from the various points in the network to PHC—have been set up. The aim is to establish communication between services and professionals in the transition between health services and to enable timely access. Users seen in PHC, when necessary, are "referenced" (referred) to other points of care. When they are seen, they must be "counter-referred", i.e., the professional must forward the respective clinical information to the unit of origin so that continuity of care can be achieved (Brasil, 2011). These instruments can be physical or computerized.
Access to specialized care	Access corresponds to the possibility of identifying, seeking, reaching, obtaining, and using the necessary health services (Levesque; Harris; Russell, 2013). From the perspective of users/population, these authors' framework incorporates various aspects of access, their corresponding barriers and interactions (Cu et al., 2021; Levesque; Harris; Russell, 2013). In addition, users identify long waiting times for specialized care after a referral as a discontinuity factor (Waibel et al., 2016).

continues...

Chart 1 – Continuation.

Dimension	Description
Continuity of care	A concept of continuity of care is adopted which involves the perception of affiliation between patients and health professionals based on a relationship of trust and responsibility over time (Haggerty et al., 2003). Haggerty et al. (2003) define three types of continuity: (1) informational, which involves users' perception of the use and sharing of information about the context, values, preferences and history of health events by the various providers; (2) managerial, related to the perception of coherence in the provision of appropriate care, in a timely manner and in the correct sequence, especially in the case of conditions that require interventions by multiple providers; (3) relational continuity, which concerns a continuous therapeutic relationship between a patient and one or more providers, which would make it possible to establish connections between discontinuous events (Haggerty et al., 2003).

Source: Prepared by the author from Brasil (2011); Levesque, Harris, and Russell (2013); Cu et al. (2021); Waibel et al. (2016); and Haggerty et al. (2003).

Results

Profile of participants: risk and vulnerability

Table 2 shows the profile of the study participants. Most can be characterized by a highly vulnerable profile, being: women (78.9%), people over 60 (55.2%); self-declared Black (71.2%); with complete or incomplete primary education (56.8%); without partners (63.2%); and the head of household (60.5%). Around half of the participants had a family income of up to one minimum wage and received some kind of social benefit. Only two participants reported having health insurance and 13% mentioned having "popular plans' or 'discount cards," which is very different from the supplementary health coverage of the municipal population (56% of the population, according to Table 1).

Table 2 - Characterization of study participants, Niterói, Rio de Janeiro, Brazil 2022

Socioeconomic aspects	N	%
Age		
“49 years	6	15.8
50-59 years	11	28.4
60-69 years	13	34.2
70-79 years	7	18.4
80 years and over	1	2.6
Race/color (self-declared)		
White	11	28.4
Brown/Mixed-race	18	47.4
Black	9	23.7
Gender		
Male	8	21,0
Female	29	76.3
Travesti	1	2.6

continues...

Table 2 – Continuation.

Socioeconomic aspects	N	%
Level of education		
Incomplete primary education	11	28.4
Primary education	11	28.4
Incomplete secondary education	5	13,2
Complete secondary education	10	26.3
Higher education	1	2.6
Marital status		
With a partner	13	34.2
No partner	24	63.2
I'd rather not answer	1	2.6
Children		
No children	5	13.2
1 to 2 children	19	50,0
3 or more children	14	36.8
Head of household		
Main provider	23	60.5
Another family member	12	31,6
Shared	2	5.3
Don't know/didn't answer	1	2.6
Family income in minimum wages (MW)		
“1	20	52.6
1-2	10	26.3
2-3	5	13.2
3-4	2	5.3
Reports having no income	1	2.6
Social benefit		
No	19	50
Yes	19	50
Which one?		
Retirement/pension	7	36.8
Continuous Cash Benefit (BPC)	1	5.3
Municipal Social Benefit	7	36.8

continues...

Table 2 – Continuation.

Socioeconomic aspects	N	%
Brazil/Emergency Aid	4	21.1
Health insurance		
None	31	81.6
Health insurance	2	5.3
Popular plan	5	13.1

Source: Authors' preparation based on the interviews.

Referral to Specialized Care: "Where's my paper that I left there with them? I still haven't seen any paper..."

Almost all of the participants reported that the main way of accessing specialist consultations in the public network was via a referral made by the FH team, especially the doctor. During the consultation, the professional would fill in the referral form and then the procedure would be scheduled by another professional in the team. Most of the time, the date of the appointment was communicated to users by the Community Health Agent (CHA) through a home visit. In many cases, the user made consecutive visits to the UBS to find out about the appointment, due to the long time without a response. The vacancy of doctors in some FH teams was pointed out as a cause of the failure to make referrals, since they were responsible for the referral requests.

In addition to the formal flow via PHC, some users, less frequently, went directly to the municipal polyclinics to schedule appointments with specialists, on specific days and at specific times. Others reported that because they had a "card" or used internal (return) appointments, the polyclinics also provided direct access to the specialist:

> *You have to go very early (to the polyclinic). When it's the day of the appointment, it's a terror* [...] *you have to be there at 6 o'clock in the morning. When you arrive, there's a lot of people, then you get there, there's that queue. It's just one day. When you get there, sometimes there's nothing left. Then only next month or two months from then.* [...] (P18/M/65).

> *I go to the polyclinic, I go to the little room, the girl makes an appointment for me, I go on that day, and I do everything right. It's great there! You don't even need to come here (UBS). Just to make a referral, then you don't need to...* (P2/F/72).

There were reports of the FH team advising people to seek private services if there was an emergency: "*Do you want to pay out of pocket or do you want us* [the FH team] to *make an appointment there? It's up to you...*" (P12/M/32).

Regarding specialized tests, the path was the same–referrals made by the FH team doctor. Scheduling difficulties were considered to be more severe as compared to consultations. Many users said they did not even know if some of the tests were carried out by the SUS and sought private services directly, even in cases of extreme financial vulnerability:

> *I had to have a full abdominal ultrasound. I paid for it there at X* [popular plan]. *I also paid for a stomach endoscopy there. I don't think you can get it at the clinic, can you? If you can, it takes a long time."* (P20/F/63)

> *Because we do the test* [privately] *to get it faster, it takes too long* [at SUS]. *If you're going to die, you die. It's awful. I'm sorry for what I'm saying, but it's the truth."* (P3/F/55)

There was a suggestion of some kind of sanction if the procedures were not scheduled within a set timeframe:

> *If it goes beyond two months, there will be a penalty. That's fine. That makes it very difficult. My father died... He died from a test that wasn't done. But it wasn't just him...* (P18/M/65)

Given so many barriers, the referral process to the SC from the PHC was perceived as yet another obstacle: "*I'm stuck here* [at the PHC]" (P14/F/51). As appointments were not made in a timely manner, or were simply not made (a fairly frequent situation), PHC was perceived as being restricted because it did not have the specialists, as well as being responsible for the delay or lack of access to SC. In the same vein, there were questions as to "why" it wasn't possible to be seen directly at any public health service:

> *It's very difficult. It's no use. This family clinic business doesn't work. You had to get the date and go there* [to a specialized service] *and make an appointment. That was the right thing to do. Now there's this business of "go to I don't know where," then there is none, then they send you somewhere else. Sometimes they send you somewhere far away, where you don't even know how to get around* (P1/F/70)

> *There's only one medical clinic here too. It's no use. I'd like an ENT, but there isn't one here. I think every health center should have everything, right? So they wouldn't have us sent elsewhere.* (P2/F/72)

> *I live in Niterói, the post is for the municipality. And you arrive at a unit, and they don't want to see you? Isn't that Niterói? Isn't the same municipality? Don't I live here? Why are they not wanting to see me? That's the barrier. It's human beings who create the barrier.* (P33/M/55)

Some narratives pointed to organizational problems at the PHC in handling referral requests, such as the lack of communication with users to monitor the scheduling process and the perception that "paper" was lost by the team.

Few users realized that the delay in scheduling could not be attributed to PHC, although they did recognize the long wait. Some narratives reproduced the impotence of the teams, signaled by the professionals themselves:

> *Then if they make the request today, it takes almost a year to arrive. But I don't think it's their fault because the paper (reference) is here. It goes down there, it's hard to get.* (P5/F/64)

> *The girls* [nursing technicians and CHWs] *said: "We can't do anything, they're in charge there* [specialized service], *we obey."* (P30/F/65)

Access to Specialized Care: restricted and privatized — "But the difficulty is so great that you end up giving up"

Given all the obstacles, users and their families forged various strategies to access SC, parallel or complementary to the use of public services.

One of the possibilities for accessing specialized consultations outside the formal flow was to go directly to municipal polyclinics. Some participants reported being linked to the University Hospital because of previous follow-ups. In the case of users who used this unit, there was great satisfaction and expectation that regular follow-up could be concentrated there. Among the reasons for this was the possibility of carrying out the tests in the unit itself, having the results in the medical records and the next appointment pre-scheduled. In some cases, the hospital was not recognized as belonging to the public network. The difficulties of access found in other services were attributed to the SUS.

The barriers to access were more significant in relation to specialized tests. Even in the public system, some participants mentioned having tests done when they went to the UPA or when they were hospitalized. All the interviewees who reported surgery had their pre-surgery tests done in private services, due to the immediate need:

> *She* [the daughter] *said: "Mom, we're going to do this test privately"* [...] *We did everything privately, otherwise we wouldn't have been able to deliver it in a month there* [at the hospital where the surgery took place]. (P22/F/83)

Of the 38 participants, 11 said they paid for specialized consultations and 30 sought tests in the private network. There were several privatized arrangements, which involved strategies such as consultations at opticians; discounts at hospitals where the family member worked; and the most frequent was direct payment at popular clinics, especially for lower-cost tests. Some users mentioned that there was some waiting at popular clinics, especially since the COVID-19 pandemic:

> *Thank God, we can pay R$30.00* [for an ECG at the popular clinic]*, but there are people who don't even have R$10.00, so sometimes people die because of that. It takes a long time. I think it should be faster, right?* (P13/F/59)

Two participants from the same UBS, who had their SAH monitored by specialists in the private network, considered that, because they had the resources, they preferred to leave the "vacancy" in the SUS for those who needed it more:

> *Why, since I have health insurance, am I going to take other people's places? So, if I pay for health insurance, it's my right to be seen by a doctor within the* [*health*] *plan.* (P26/F/66)

As well as carrying out the test, access to the results was another much-reported difficulty, since in the vast majority of cases they had to be sought out by the user themselves. To a lesser extent, some went directly to the UBS. Along the way, some of those interviewed said that the results were lost or took so long that they had to be repeated:

> *My last test took too long... When I went to the specialist, she told me that I needed to have another one because it took too long from the test to the appointment.* (P34/F/42)

> *Tests take a long time and several of my test results have already vanished here* [at the UBS]*. Once, I came here, had a test, and it disappeared. The doctor looked for a while and said: "It's gone from my table." She asked for another one, the electrocardiogram.* (P2/F/72)

Access to specialized services was hampered by barriers related to paying for transport, even within the municipality itself. Some participants said they walked, hitchhiked, took the bus, biked, or used Uber, in a context of very low income.

As a consequence of restricted access, some narratives suggested worsening of hypertension and comorbidities (13 of the 38 interviewees reported having diabetes) with visits to the UPA and hospital emergency rooms:

> *I went to hospital X* [hospital emergency] *feeling unwell. Everything was high, glucose, cholesterol, blood pressure, then the electrocardiogram showed a change, and he told me to go to the health post so he could refer me to a cardiologist. And I'm still waiting for that cardiologist today.* (P9/M/59)

To the extent that the "resolution of the case," in the perception of many users, was dependent on specialized consultations and tests, the gateway via PHC was considered another barrier to complete care:

> *Look, I really like the service girls* [nursing technicians and CHA]*, but I can't solve my problems here. It's just that, in reality, every test we need has to be done at the clinic. Theres no way around it.* (P8/F/42)

Narratives of discontinuous care: "this looseness things discourage me..."

Almost all of the participants said they had no link with any SC professional, mentioning that they were seen "*wherever there was a slot*" (P14/F/51). There were also frequent reports of not knowing about specialized services, due to not using them.

None of the interviewees perceived communication between PHC and SC professionals. With regard to both levels of care, narratives like "*you have to tell everything again. Because it's like everything is reset. It's like a new consultation*" (P38/F/49); "*each professional in their own 'square'*" were very recurrent (P31/M/65). Some participants attributed the need to repeat the clinical history to the lack of reading of medical records in PHC and SC. Delegating this task to users or family members required them to remember and understand all the guidelines and prescriptions in order to pass them on to the professionals during the various appointments. The following narratives strongly express the perception and dissatisfaction with the lack of continuity of care:

> *I think it's uncomfortable for you to say everything again if there's a medical record. And I think that if it's a group of doctors, a specialty, they have to follow up our medical records with the main doctor, the family doctor. Our medical records are already our whole life... So you don't need to go to my specialty and talk about when I started. I think that if there was an exchange, a good internet, a good job, when I arrived with my medical record number in that specialty, everything would already be prescribed. You have to say it all over again! I'm not smart enough, I didn't go to college, but I know what bothers me. Got it* (P11/F/48)

> *Because there's no continuous treatment, there isn't! Because here it's every man for himself and God for all.* (P14/F/51)

Regarding PHC, there were reports that the clinical information provided by users was recorded in the medical records, although there was no mention of receiving and delivering the counter-referral: "*To give it to them there* [at PHC], *they* [specialists] *don't do it. They just give me the prescription and that's it"* (P2/F/72).

Professional turnover was indicated as a factor that aggravated the problem of informational continuity, due to the need to repeat the clinical history, and relational continuity, due to the difficulty in establishing a bond. Some participants pointed out that polyclinics had lower professional turnover and better organization of the work process, a factor that was valued and facilitated bonding:

> *You have to explain, because we go to one, and then it's another one* [at the PHC]. *Especially this eye treatment. We think it's the same doctor, then we have to say it all over again.* (P20/F/63)

> *Everything is organized there. Polyclinic X is very good* [...]. *It's the same doctor, she never misses a day, when she's on vacation, she says: "December you're coming on that day." I made the appointment for her properly, the service there is great.* (P2/F/72)

Despite the long waiting time for access to SC, which influenced the evaluation given by means of a score attributed to PHC and SC services—including the university hospital, when used—higher scores were obtained by specialized services. Once they had received care, users were satisfied. One participant considered it a loss not to be seen at the hospital anymore, mentioning that she knew the professionals there and that the service cared about the patient, as she received follow-up calls (P8/F/42).

Discussion

Evidence indicates that PHC is the preferred gateway to the SUS, as well as being the most appropriate place to monitor people with SAH, among other aspects, because it is able to guarantee protection against the risks of excessive and inappropriate use of diagnostic and therapeutic procedures (Norman; Tesser, 2009). On the other hand, analyzing experiences of transition between levels reveals a set of restrictions and mitigation of comprehensive access to health (Coleman, 2003). The consequences are numerous.

The participants in the study were in a situation of great vulnerability, an aggravating factor when it comes to controlling SAH, which makes the SUS an essential source of healthcare. The PNS shows that SAH is higher in people with low levels of schooling, i.e. those more affected by exposure to risk factors, adverse socioeconomic conditions, difficulties in accessing health services and guidance and means to adopt healthier lifestyle habits (Malta et al., 2022), likewise observed in this study.

When interacting with the ED, users experience different moments/waiting times, one of which is the delay between the referral and the scheduling of the specialized procedure (Farias et al., 2019). The instruments that materialize the beginning of the transition between care levels were the "referral and counter-referral guides" known as the "paper," the "referral." The experiences strongly indicated a process that in no way comes close to proposing care regulation with a view to guaranteeing the organization and prioritization of access and care flows according to criteria of equity and opportunity (Brasil, 2011). The referral document was not recognized as a mediator of timely access, nor was the counter-referral (which was never received) understood as a right (Oliveira; Silva; Souza, 2021).

In the study, scheduling by the FH teams and subsequent communication to users predominated. However, the delay in receiving feedback led to consecutive and anguished visits to the UBS, the search for points in the network that were permeable to direct scheduling, as well as the search for private services. "There's nothing we can do..."—a statement by a PHC professional according to a user, represents a summary of the impotence of PHC in guaranteeing continuity of care (Cecilio et al., 2012).

The barriers that begin with the referral process, among other aspects, reflect the restrictions on access to SC in the SUS. They produce negative effects on the patient's experience in their care pathway, such as physical and mental distress for patients and families due to the delay in care; more complementary tests; emergency care; hospital readmissions, as well as resulting in dissatisfaction due to the lack of coordination of care (Hudon et al., 2022), as also observed in this study.

The search for escape routes within the public network itself, including the expectation of longitudinal links to hospitals, were strategies designed by users. The exacerbation of chronic events was present, aggravated by comorbidities, intensifying the use of public emergency rooms. The possibility of doing "everything in one place," present in other studies (Almeida; Casotti; Silvério, 2023), rather than valuing specialized procedures, should be analyzed in the light of the numerous barriers that stand in the way of continuous and comprehensive care.

Long waiting times cause problems of various kinds for society, families and individuals who may experience worsening of the disease, psychological problems or even death (Farias et al., 2019). The delay in scheduling specialized tests, compared to consultations, was even more significant. Given the need for surgery, preoperative exams were carried out in private services, precisely because of the need for timely provision. The search for UPAs was a possibility for tests. This mosaic of arrangements forges an insecure and discontinuous pattern of access to health services, with catastrophic costs, since it is dependent on users and families.

In the absence of timely access and the frustration of their own expectations, users found access to specialties not covered by the SUS in private services. The Popular Health Clinics stand out, companies that offer consultations and diagnostic tests at so-called popular prices. The search was mainly for tests, as reported in another study in the same municipality (Almeida; Casotti; Silvério, 2023). The presence of these clinics is part of the reconfiguration of the private health market in the country. They operate a medical-centered model, with no guarantee of the quality of diagnostic procedures, multidisciplinary work or guarantee of actions for complete care (Campos et al., 2023).

As in other studies (Oliveira; Silva; Souza, 2021), the difficulties in accessing back-up care were attributed to PHC, which was blamed for the success or otherwise of scheduling and the long waiting times for SC. In this sense, PHC presents itself "as an observatory of the difficulties in accessing medium and high-complexity services," sharing its impotence with users (Cecilio et al., 2012, p. 2900). Furthermore, waiting time is a determinant of dissatisfaction with health services and is clearly perceived as an obstacle to access—the longer it is, the more dissatisfied users are (Ferreira et al., 2023).

As a result, the role of gateway and the composition of the generalist team, pillars of the FHS model, were questioned. The direct and deliberate search for any service in the municipal network was demanded, above all by focal specialists who were considered capable of solving health problems. Even the universal right, via the public system, came to be questioned, with a perception that the constitutional principles of comprehensiveness and equity of the SUS were only fulfilled under exceptional and specific conditions (Santos, 2022).

Transport to access specialized services, even if they are located in the municipality, was a barrier, with effects on access to health for populations with unfavorable socioeconomic conditions, as in this study. In the same direction, although situated in the field of service organization, there was the lack of strategies for receiving test results. When they were properly carried out, they were either lost or had to be sought out by users, which meant more journeys with time and transportation costs. This whole process increased the waiting time for diagnosis and encouraged repeat tests, one of the effects of uncoordinated care (Espinel-Flores et al., 2022).

There was no perception of communication between PHC and SC providers. On the contrary, experiences have emerged that indicate the need to repeat the clinical history as an effect of the lack of informational continuity (Espinel-Flores et al., 2022; Waibel et al., 2016). Although patients and their families are elevated to the position of the only link between the different points of care, with the mission of facilitating transitions of care, this responsibility is not accompanied by the necessary skills and information (Coleman, 2003).

Although the defense is for the FH team to coordinate care, what we see from the users' perspective is a vacuum in this role. "Each professional in their own field" summarizes a set of uncoordinated experiences. Lack of time; lack of personal relationships and opportunities to meet other professionals; lack of information and feedback loops; and lack of responsibility and autonomy are factors related to low interprofessional collaboration (Khatri et al., 2023) and require educational and management measures to address them.

Professional turnover was perceived as a factor that aggravated the lack of informational and relational continuity. Measures such as defining roles in interdisciplinary teams, sharing routines and good working conditions are capable of reducing stress and care pressure, with the possibility of affecting turnover (Ljungholm et al., 2022). In addition, these factors can help professionals establish closer relationships with users, better knowledge transfer and shared work (Ljungholm et al., 2022).

The diversity of experiences anchored in the reality of the participants in the transition between PHC and SC allowed for a dense analysis of reality, which does not exclude other perceptions and interpretations, when considering, for example, the perspective of health managers and professionals. Another limitation of the study is the fact that no medical records or municipal indicators for monitoring SAH were analyzed, which could have provided elements for data triangulation.

Final considerations

Users' perspectives on the transition between PHC and SC offer an opportunity to gain a systemic understanding of the barriers that stand in the way of comprehensive, integrated health care. Considering the experiences of transition between levels reveals restrictions and mitigation of comprehensive access to health, with repercussions on credibility and satisfaction with the SUS. It should be noted that the problems presented are similar to those found in other contexts with more adverse socioeconomic and health conditions, such as smaller municipalities with low capacity to provide SC in their own territory. Given that FHS coverage is targeted at part of the population in areas of greater vulnerability and that the study setting is a municipality with favorable economic indicators, it is worth asking about possible obstacles to the implementation of policies and actions to guarantee timely access to SC, with continuity and coordination by the FHS teams.

Despite the need to assess the sufficiency and timeliness of access to SC, possible interventions include: (1) the implementation of electronic medical records in the HCN, in order to reduce repetition and loss of test results and clinical history, or even the induction of manual referrals and counter-referrals; (2) strategies to promote personal contact and interprofessional collaboration in the HCN through joint continuing education and matrix support; and (3) measures to qualify the care regulation process. Mitigating precarious employment relationships, given that turnover contributes to the fraying of ties, should be a priority on the political agenda. No less important seems to be the need to change the care model to one that is, above all, people-centered, with the promotion of multiprofessional teamwork in PHC for shared monitoring of chronic conditions and increasing its resolution capacity.

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Contribution of the authors

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